

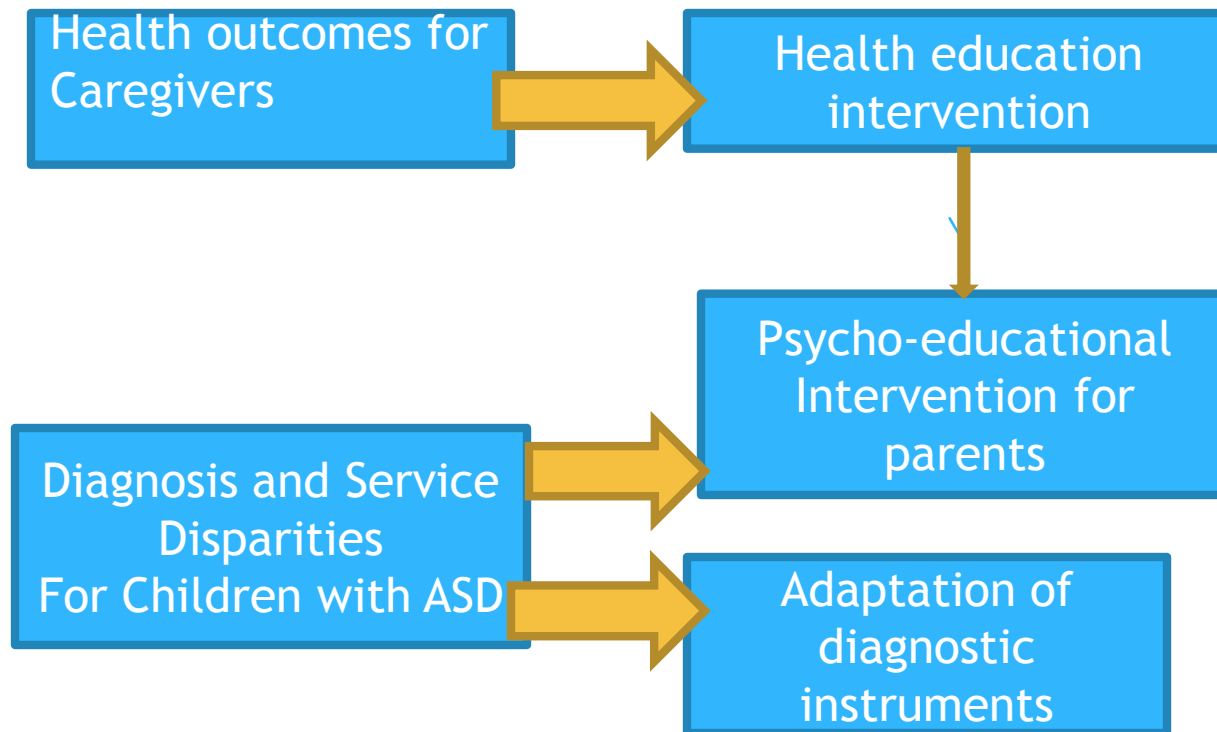
# ADDRESSING HEALTH AND SERVICE DISPARITIES FOR DIVERSE FAMILIES OF CHILDREN WITH AUTISM AND DEVELOPMENTAL DISABILITIES



# OVERVIEW OF PRESENTATION

- Health and Well-being among Latino and Black mothers of children with developmental disabilities
  - Overview of research findings
  - Health education intervention for family caregivers
- Latino children with autism
  - Disparities in diagnosis & services
  - Educational intervention for parents to reduce disparities

# FROM OBSERVATIONS TO INTERVENTIONS



# LATINO AND BLACK MOTHERS AND THEIR HEALTH

- ◉ Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago (NIDRR funding)
- ◉ John A. Hartford Foundation Geriatric Social Work Faculty Scholars Program
- ◉ Waisman Center at the University of Wisconsin-Madison
- ◉ Student: Matthew Smith

# BACKGROUND

- ◉ More than half of adults with developmental disabilities live with their families
- ◉ Latinos and African Americans with developmental disabilities are more likely to live with their families
- ◉ people of color experience environmental contexts and ecological circumstances that are not shared by whites
- ◉ Chronic exposure to many stressors
- ◉ Health disparities - especially chronic conditions

# STUDY 1: METHODS

- ◉ National Health Interview Survey (NHIS)
  - multi-purpose health survey conducted by the National Center for Health Statistics (NCHS), Center for Disease Control and Prevention (CDC)
  - over-sampled both Latino and African American populations
  - Used 3 years of the NHIS combined to ensure large enough DD minority sample

# SAMPLE

- ◉ 83 Latina and 79 Black American mothers who were 40 and older and co-resided with a child with a DD
- ◉ Mean age of the persons with DD was 17.9 (SD = 11.3)
- ◉ 59.4% were male
- ◉ Majority identified as having mental retardation, or other developmental disability
- ◉ Comparison- 1667 Latina, 1087 Black mothers with no caregiving responsibilities

# MEASURES

## ◉ Health outcome measures:

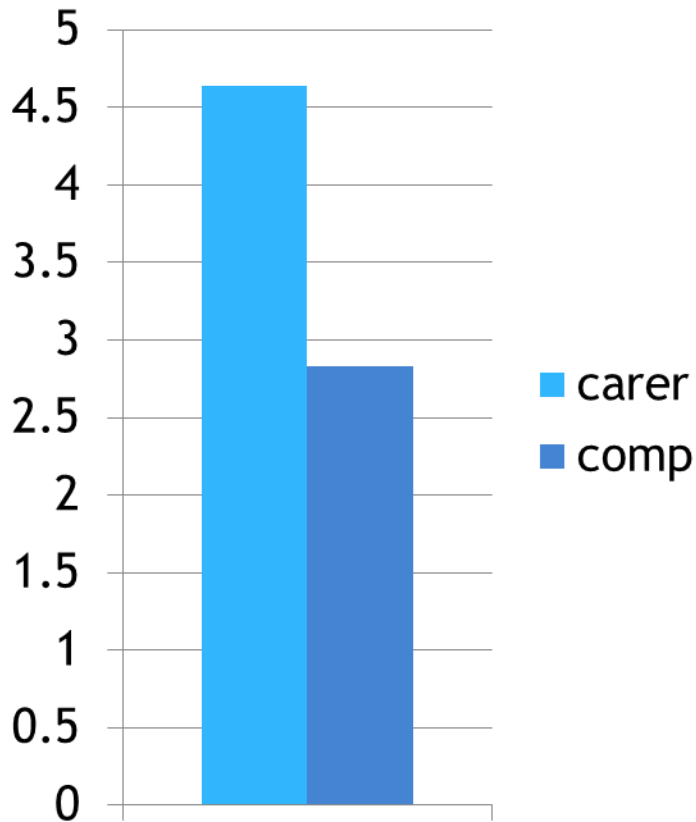
- Diagnosed with hypertension, heart problems, asthma, diabetes
- Conditions that limit activity: arthritis, hypertension, diabetes
- 5 depressive symptom items

## ◉ Health behaviors, use and access

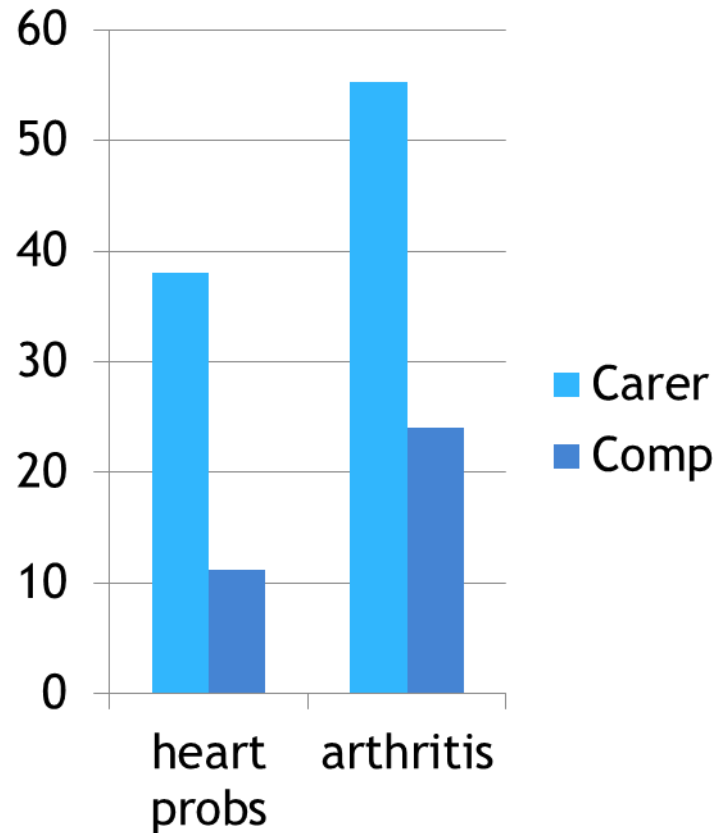
- Health behaviors: smoking, drinking, exercise, obesity
- Health care use: have seen mental health professional, general practitioner, OT or PT
- Access: can't afford MH care or prescription meds, have insurance



# LATINA HEALTH OUTCOMES

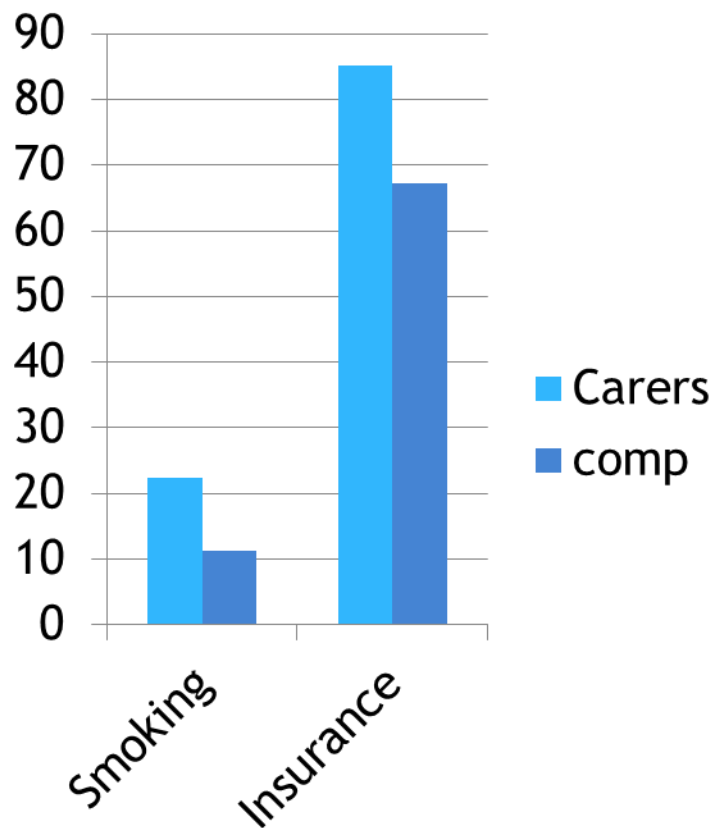


Depressive symptoms

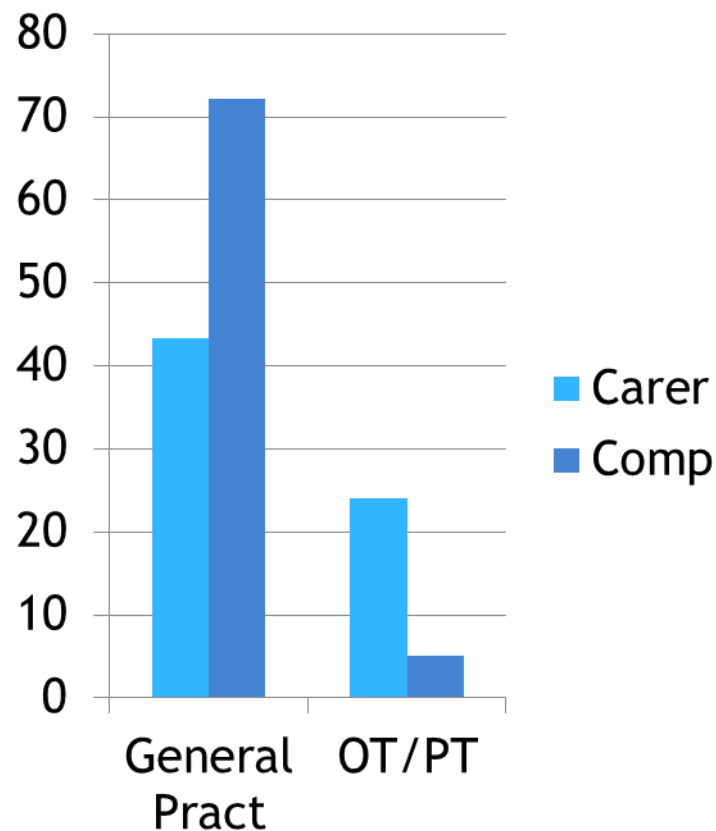


Chronic health conditions

# HEALTH BEHAVIORS, ACCESS & USE

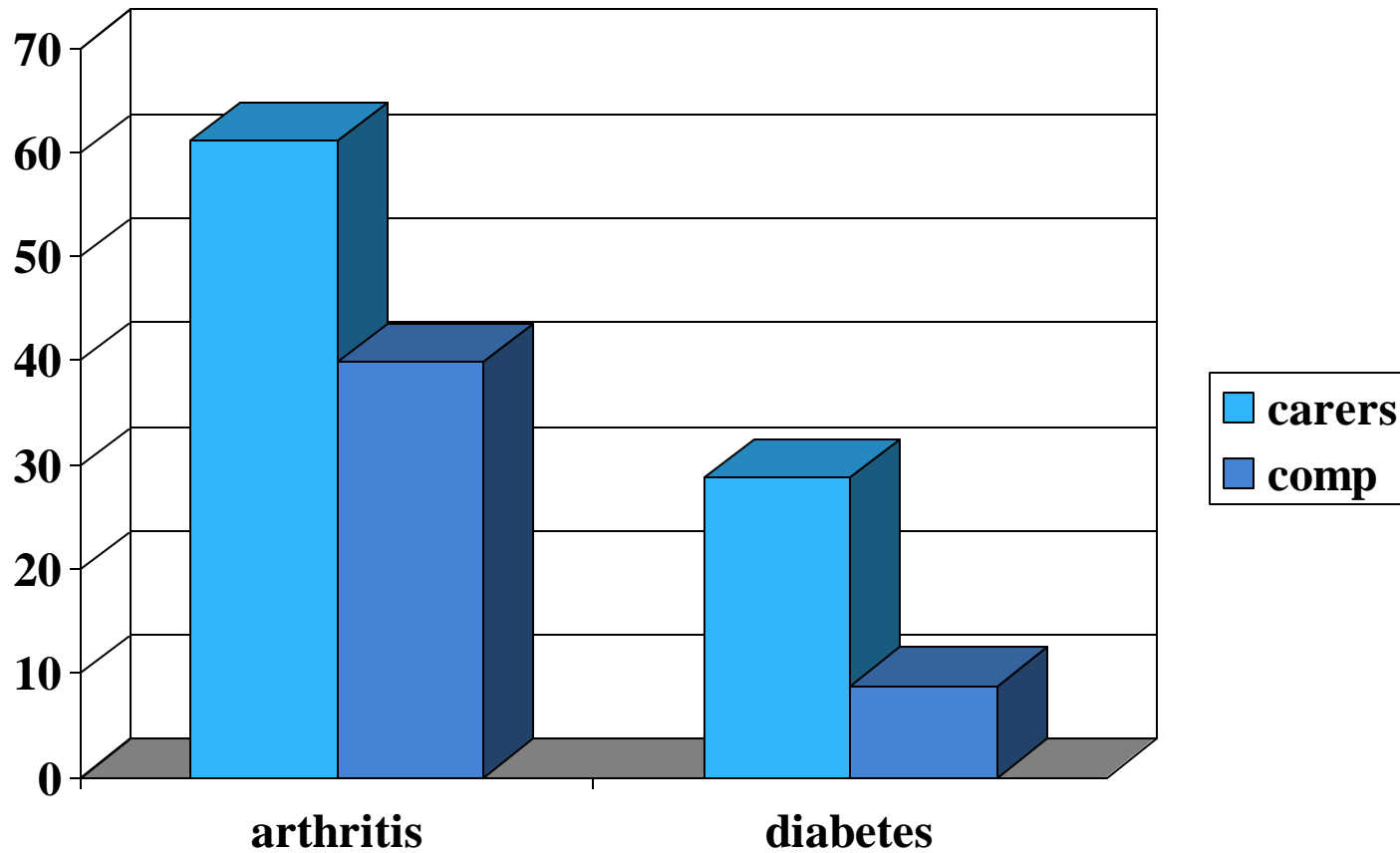


Midlife Latinas

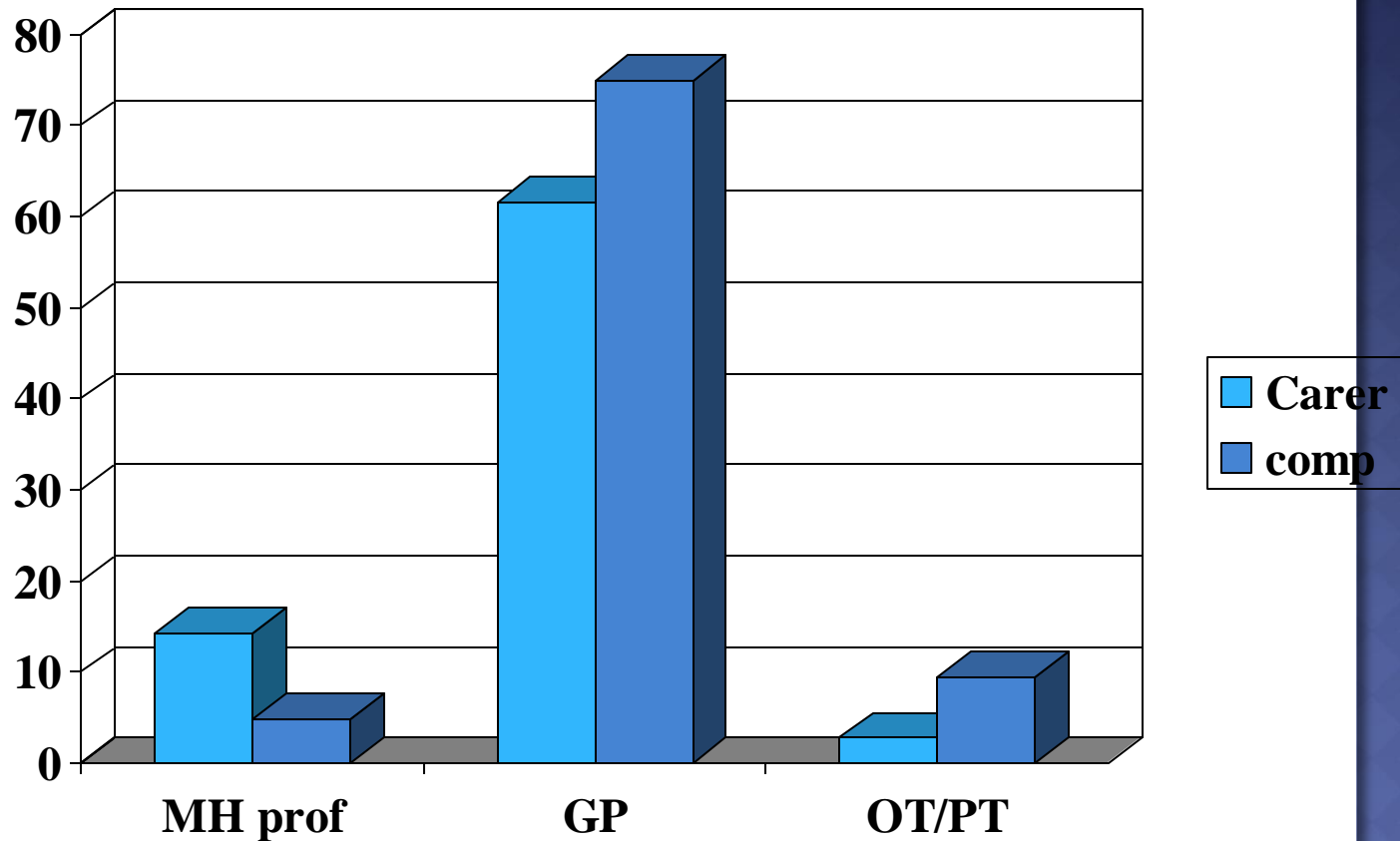


Older Latinas

# BLACK CAREGIVER HEALTH OUTCOMES



# HEALTH CARE UTILIZATION: BLACK AMERICAN WOMEN



# SUMMARY

- ◉ Older caregivers were more likely to report having physical health problems than older non-caregivers
- ◉ Caregiving was associated with more depressive symptoms for Latinas
- ◉ Caregivers less likely to see doctor
- ◉ Black caregivers less likely to use OT services and more likely to use mental health services
- ◉ Latina midlife caregivers more likely to have insurance and to smoke

# PRACTICE IMPLICATIONS

- ◉ Services need to focus on not just the person with IDD, but also the parental caregivers
- ◉ Mothers need help focusing on their own health care needs
- ◉ Interventions need to address this in a culturally sensitive way

# DEVELOPING INTERVENTION

- ◉ By Caring for Myself, I Can Care Better for My Family (Al Cuidarme a Mi Puedo Cuidar Mejor a Mi Familia)
  - Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago (NIDRR funding)
  - Waisman Center at the University of Wisconsin-Madison
  - Students: Rebecca Paradiso, Linda Serna, Elizabeth Miranda, Marian Slaughter

# BACKGROUND

- ◉ Goal was to develop an intervention that focused on the caregiver's health
- ◉ Family caregivers save the state in dollars that would be spent on residential facilities
- ◉ Need to invest in family caregivers and recognize challenges they face



# USING PEER HEALTH WORKERS

## ◉ Promotora de Salud

- live in the same community, speaks the language of those served as well as the language of the dominant culture
- understand and are involved in the host community
- Serve as a communication bridge between their communities and the "service establishment,"
- Are respected and visible, yet shares a common identity with the members of the community
  - We add the requirement that the promotora be a mother of a child with an IDD

# PROCESS & STEPS

- ◉ Developed Manual
  - used internet and consulted with Latino community
- ◉ Recruited promotoras and participants
  - Through support groups and agencies that serve Latino families of children with IDD in Madison and Milwaukee
- ◉ Provided 12-15 hours training to promotoras
- ◉ 7 Promotoras conducted 8-9 home visits to 27 participants

# PROMOTORAS IN TRAINING



# PROMOTORAS



# MANUAL CONTENT

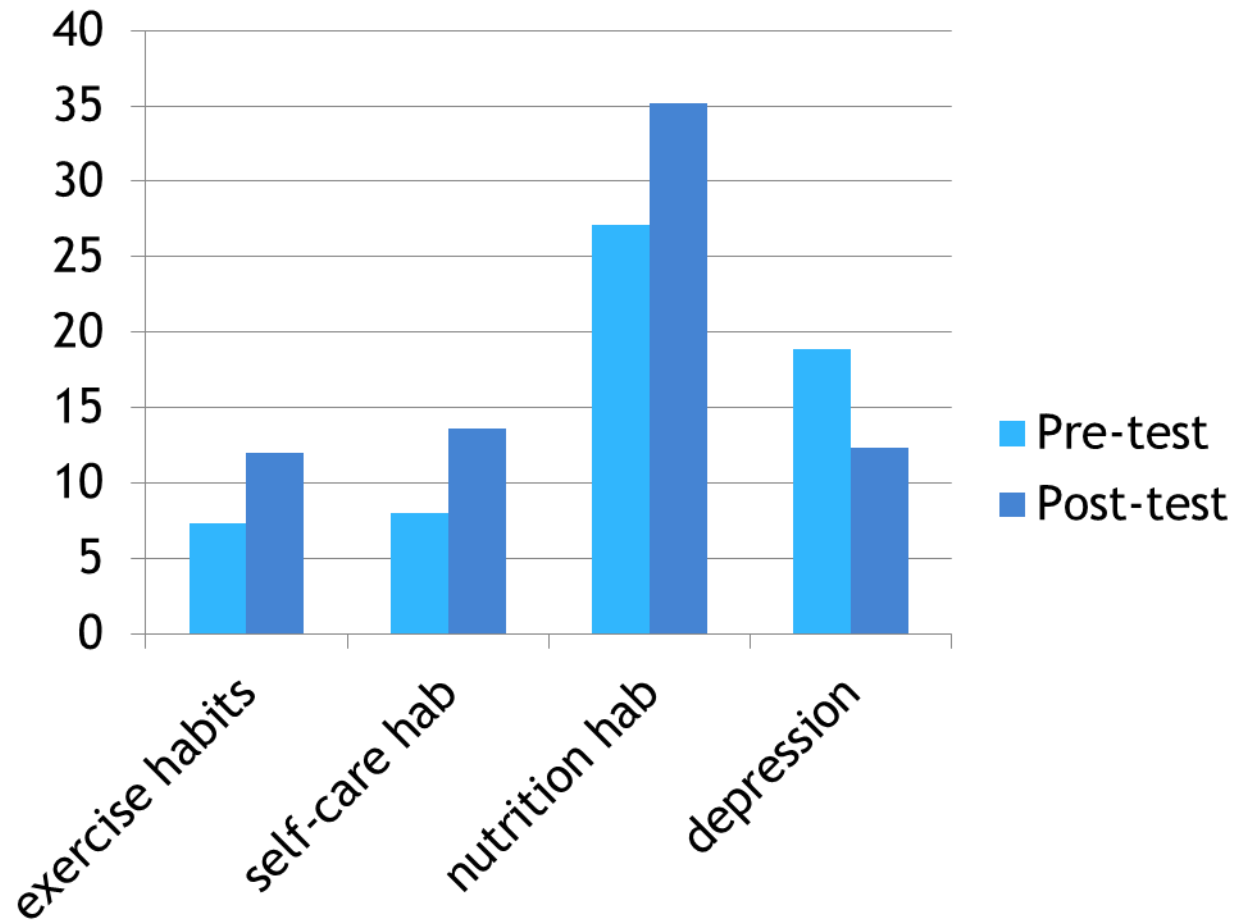
- ◉ Session One: Introduction, pre-test, and discussion of taking care of oneself
- ◉ Session Two: Health care
- ◉ Session Three: Well-being activity
- ◉ Session Four: Nutrition
- ◉ Session Five: Exercise
- ◉ Session Six: Stress and depression
- ◉ Session Seven: Including others
- ◉ Session Eight: How to sustain growth and post-test
- ◉ Folder of Resources



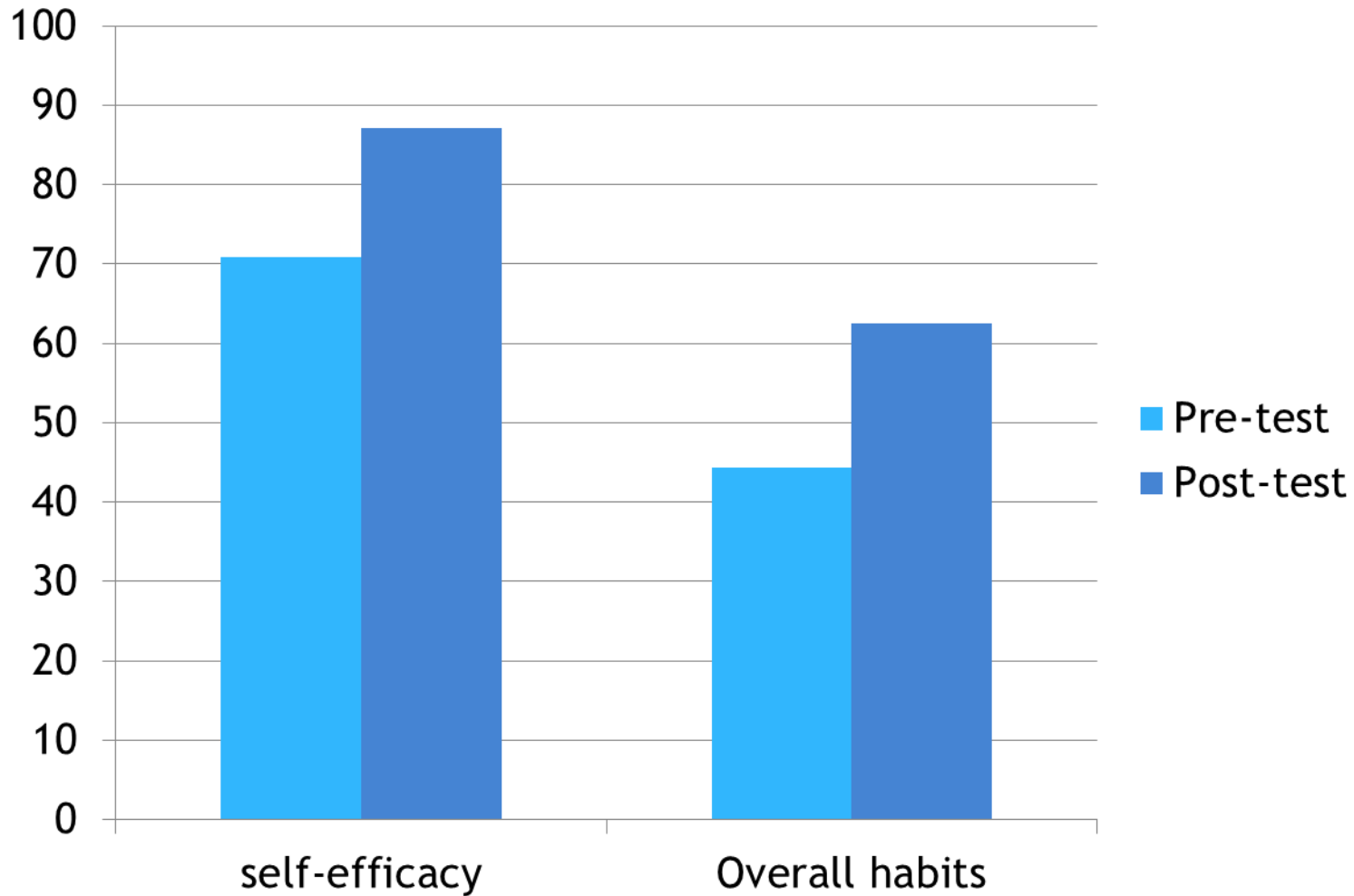
# PRE AND POST-TEST MEASURES

- Depressive symptoms (CESD)
- Positive health behaviors (self care, nutrition and exercise habits)
- Health related self efficacy

# PILOT RESULTS IN WISCONSIN



# PILOT RESULTS





# RANDOMIZED TRIAL IN CHICAGO



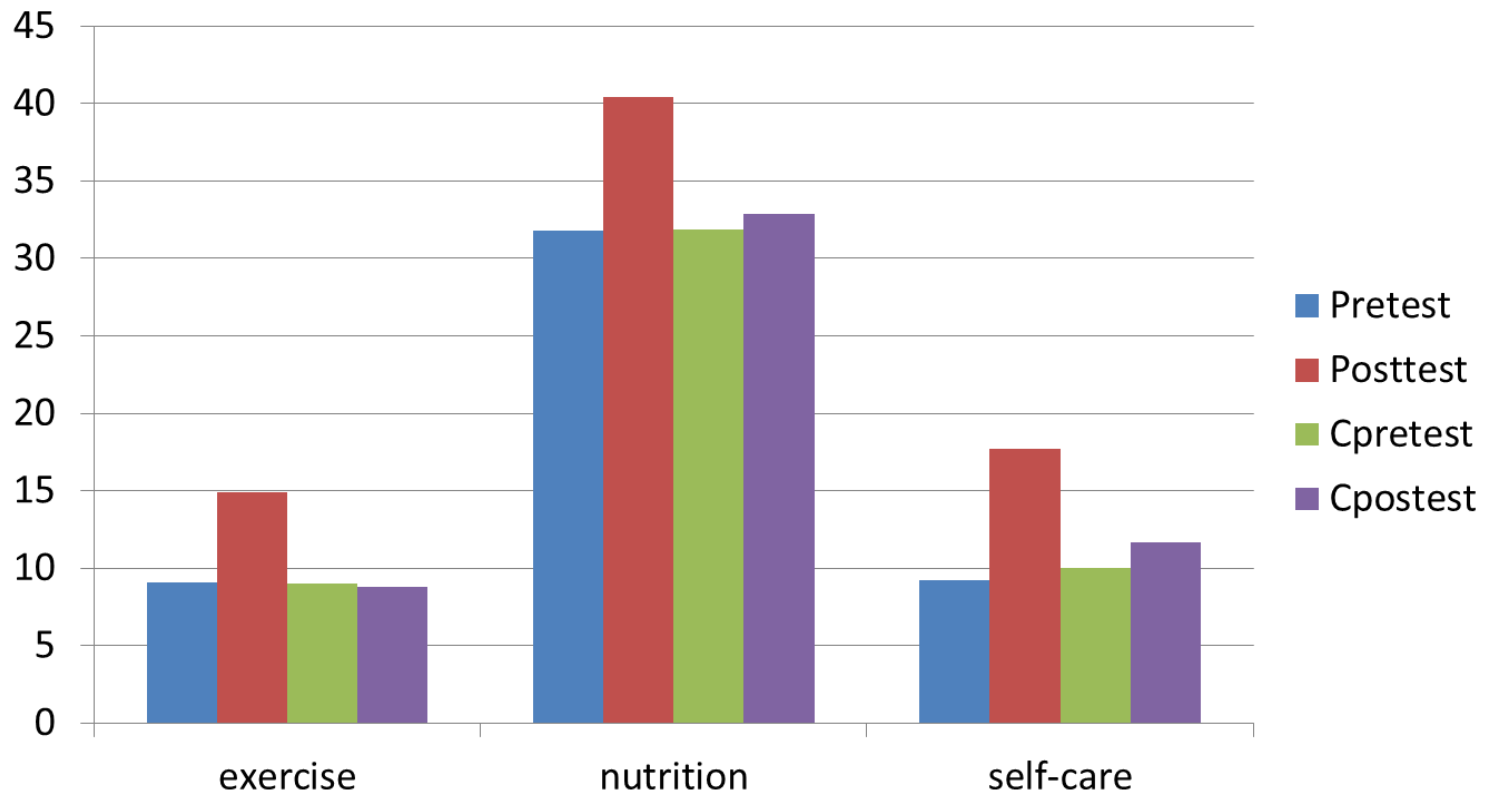
# WORKING HARD IN TRAINING



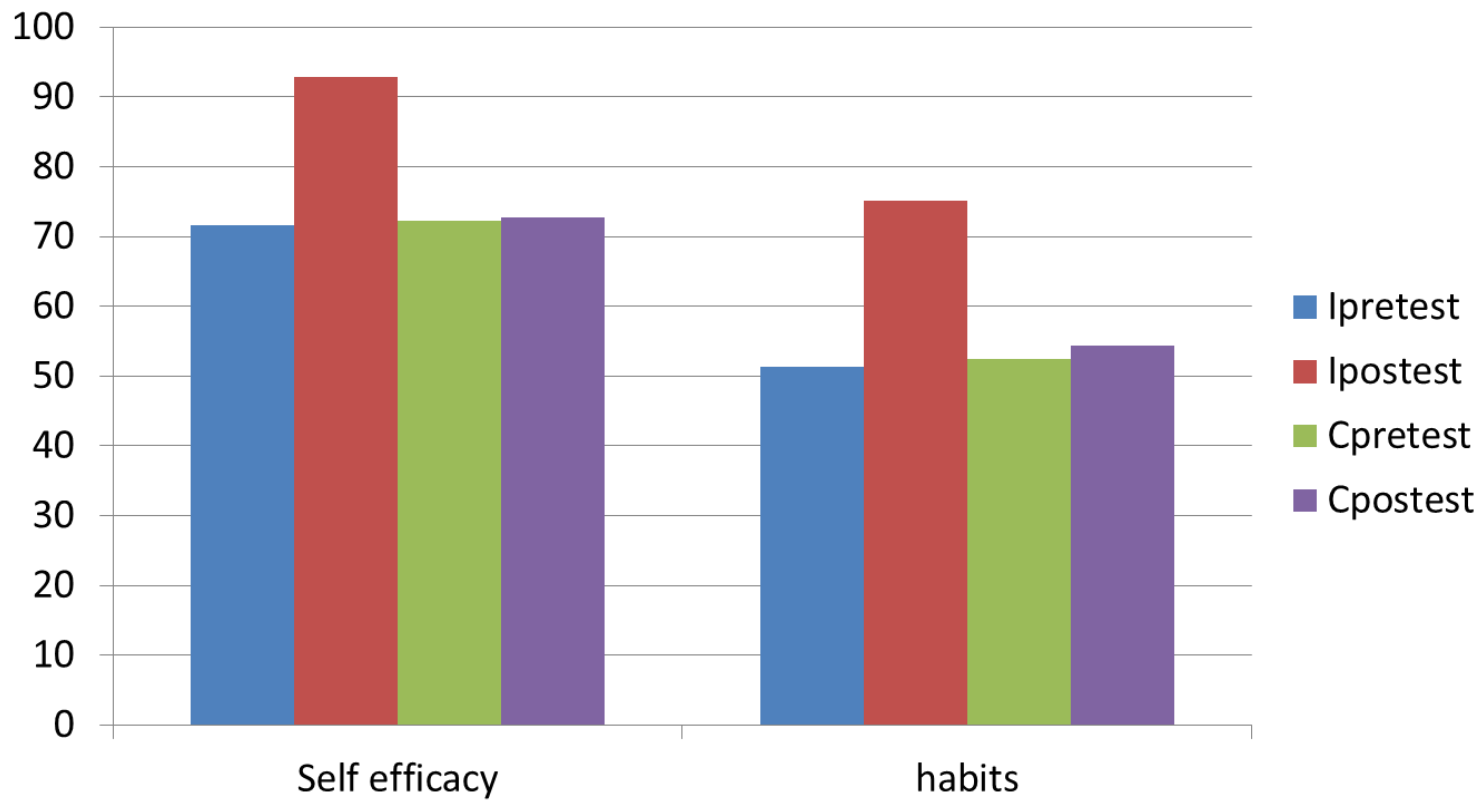




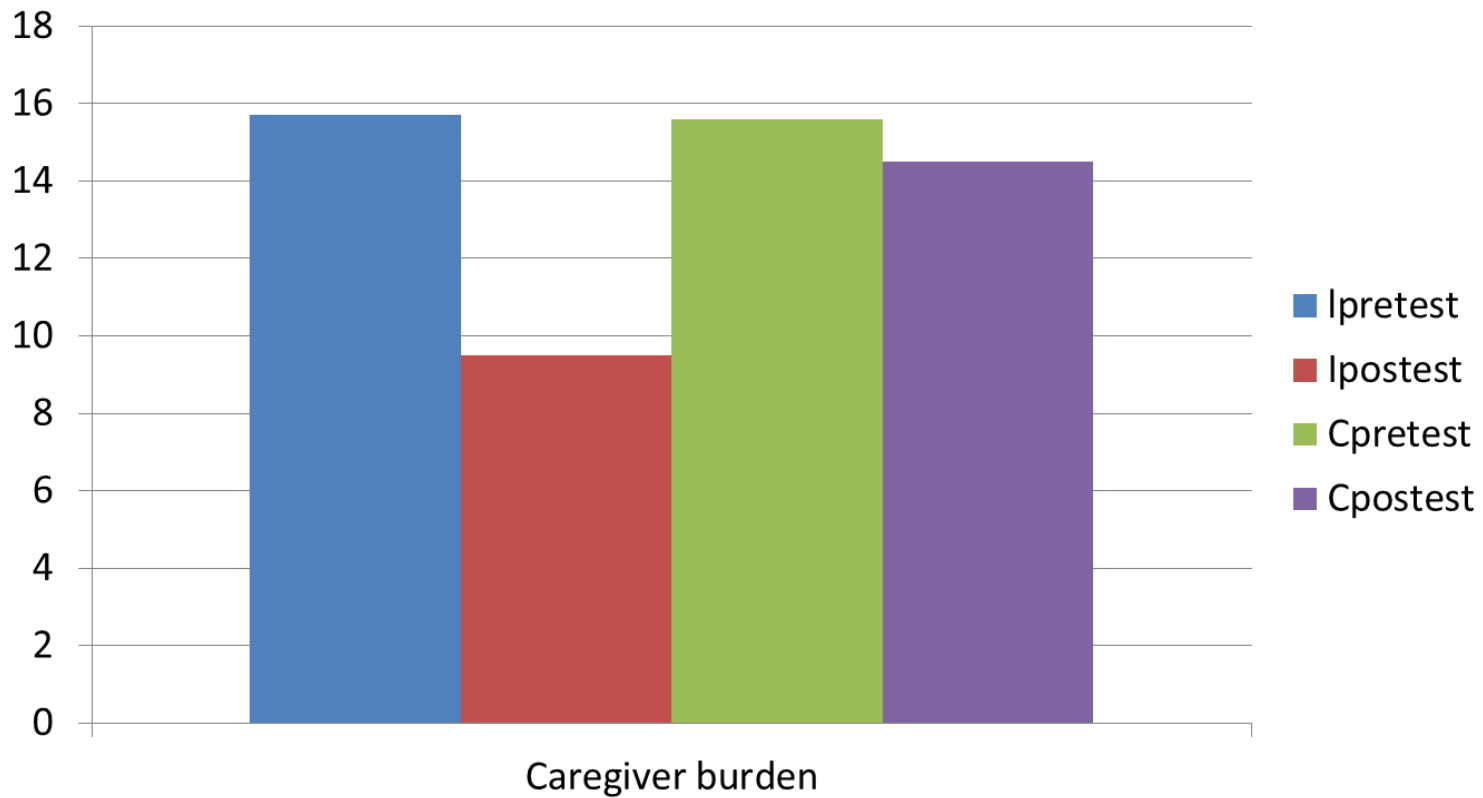
# PRELIMINARY RESULTS



# SELF EFFICACY & OVERALL HEALTH HABITS INCREASED



# CAREGIVER BURDEN REDUCED



# NEXT STEPS: OTHER COMMUNITIES

## ◉ Adapt for African American Community

- Received funding from United way and Morgridge Center
- Catholic Charities is nonprofit partner
- Conducted focus groups to adapt manual
- Trained 2 community health educators who are visiting families now

# DISPARITIES IN SERVICES FOR CHILDREN WITH AUTISM

- ◉ Disparities in health care nationally
- ◉ Disparities in specialty services in Wisconsin
- ◉ Intervention to address disparities



# DISPARITIES IN HEALTH CARE FOR CHILDREN WITH AUTISM AND OTHER DEVELOPMENTAL DISABILITIES

- ◉ Co-Authors: Susan Parish (PI), Roderick Rose, Jamie, Swaine, Maria Timberlake
- ◉ Funder: Maternal & Child Health Bureau, HRSA grant # R40MC19927

# BACKGROUND

- Overwhelming evidence of persistent, pervasive racial and ethnic health care disparities for nondisabled adults
- Relatively little is known about the extent of racial and ethnic health care disparities of children; similar general trends are obvious
- Some evidence of later diagnosis for Latino and Black children with autism



Some evidence of disparities in health care for children with special health care needs

# DATA SOURCE

- 2005-06 National Survey of Children with Special Health Care Needs
- Random-digit dialed telephone survey representative of US non-institutionalized civilian population < 18
- 5,658 children with developmental disabilities.
  - Children with developmental disabilities & autism identified from 4 questions: "To the best of your knowledge does [child] currently have...?"
    - Autism/autism spectrum disorder
    - Down syndrome
    - Mental retardation or developmental delay
    - Cerebral Palsy

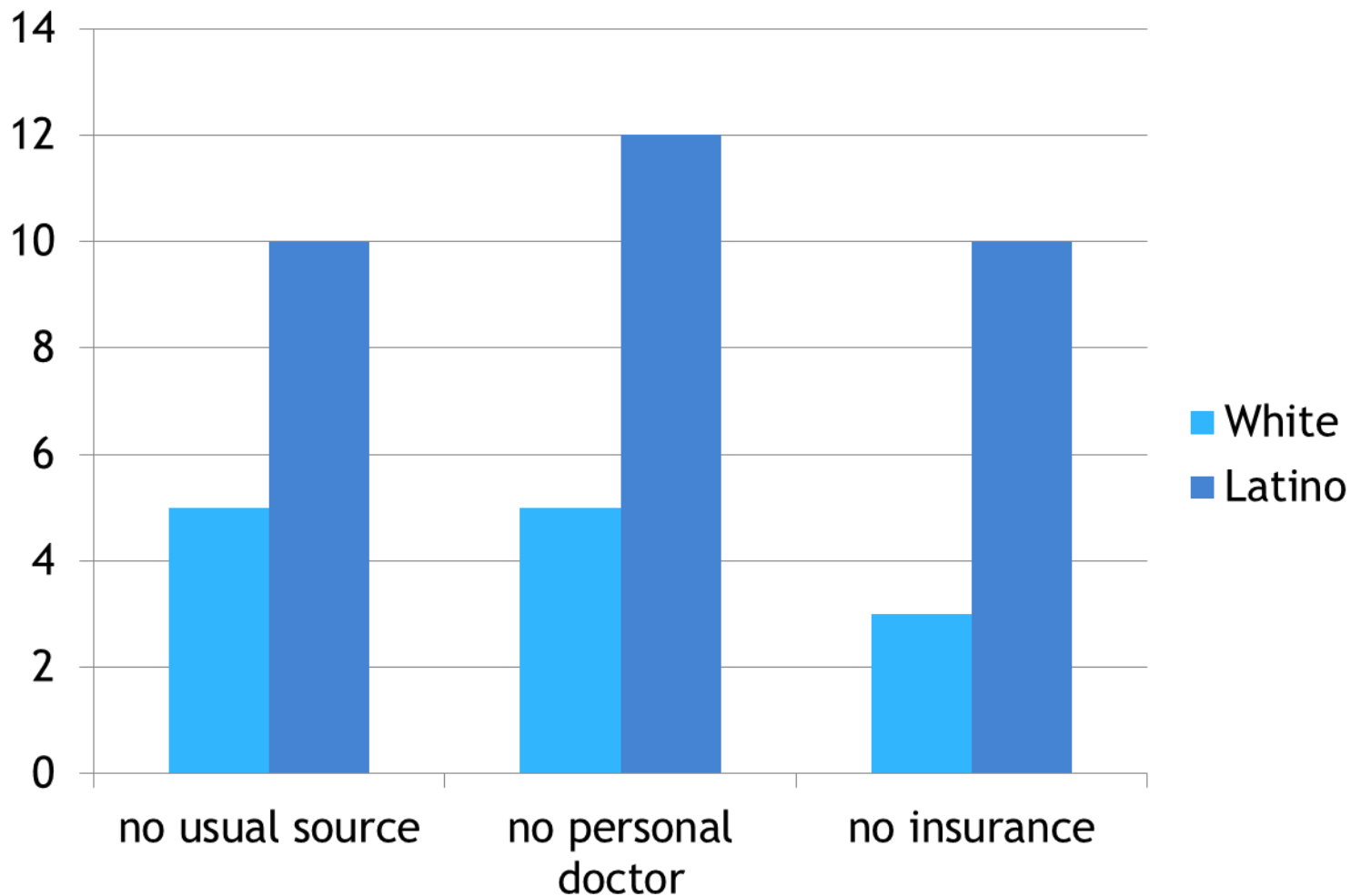
# SAMPLE

- Among children with DD, there were 682 Black children, 664 Hispanic or Latino/a children, and 3,762 White children
- 37% of all DD children were described by caregiver as having autism; 29% among Blacks; 32% among Hispanic; 40% among Whites
- 51% of all DD children lived in families < 200% FPL; 72% among both Black and Hispanic families; 41% among Whites
- 35% girls (no sex differences across race/ethnicity)

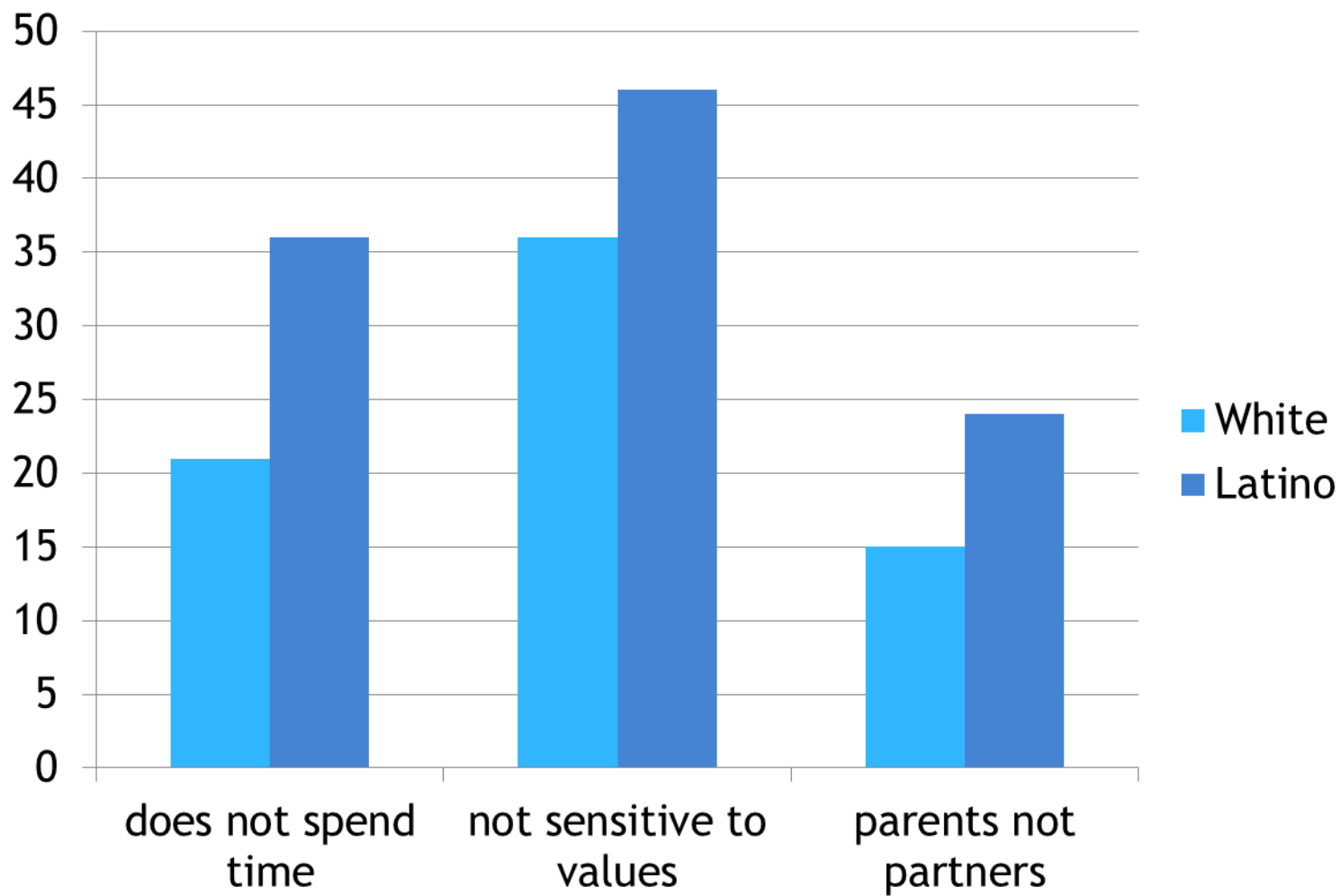
# DEPENDENT MEASURES OF HEALTH CARE

- Health Care Access
  - Usual source of care
  - Uninsured in last year
  - Needs not met by insurance
- Health Care Utilization
  - Care delayed or foregone in last year
  - Difficulty using services
  - >10 visits
  - Unmet routine service needs
- Health Care Quality
  - No personal MD
  - MD doesn't spend enough time
  - Provider doesn't listen
  - Provider not sensitive to cultural needs
  - MD does not make parent feel like partner
  - Not satisfied with health care

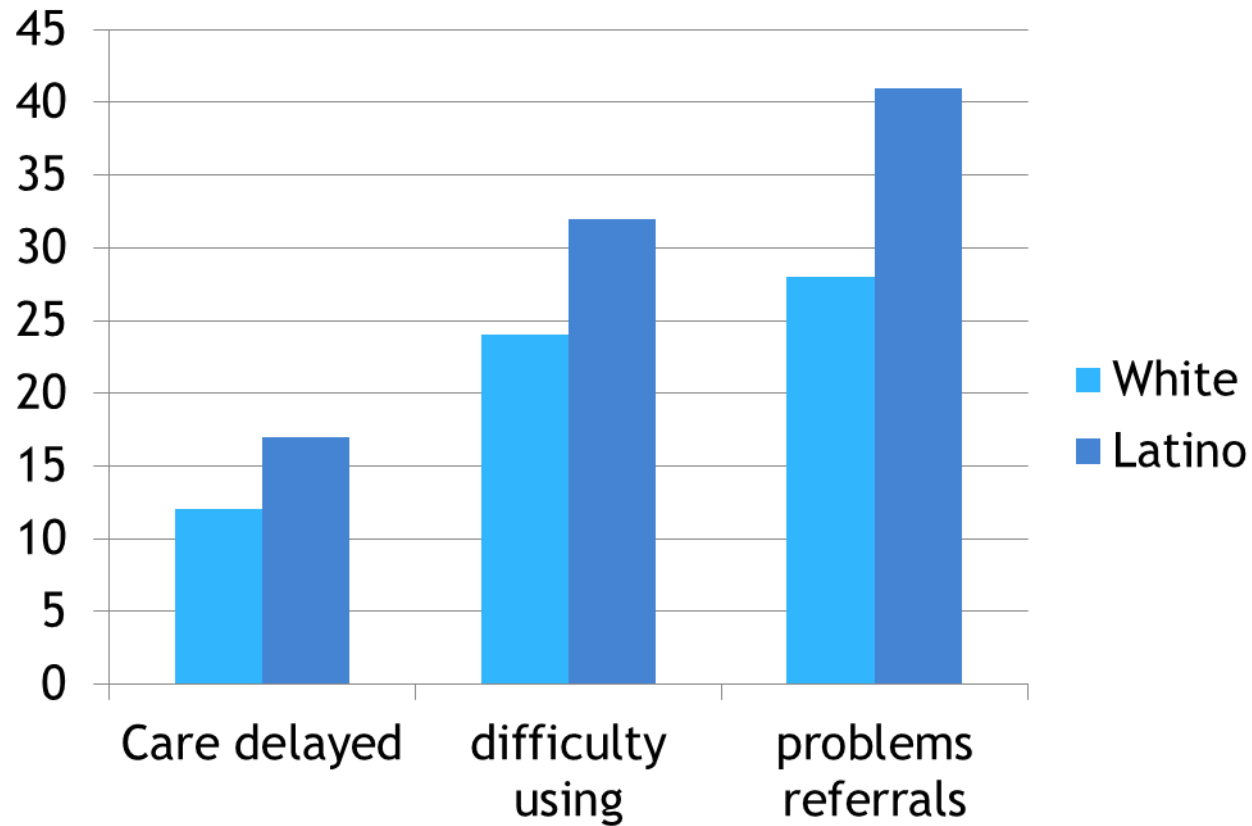
# LATINO CHILDREN AND ACCESS



# LATINO CHILDREN AND QUALITY

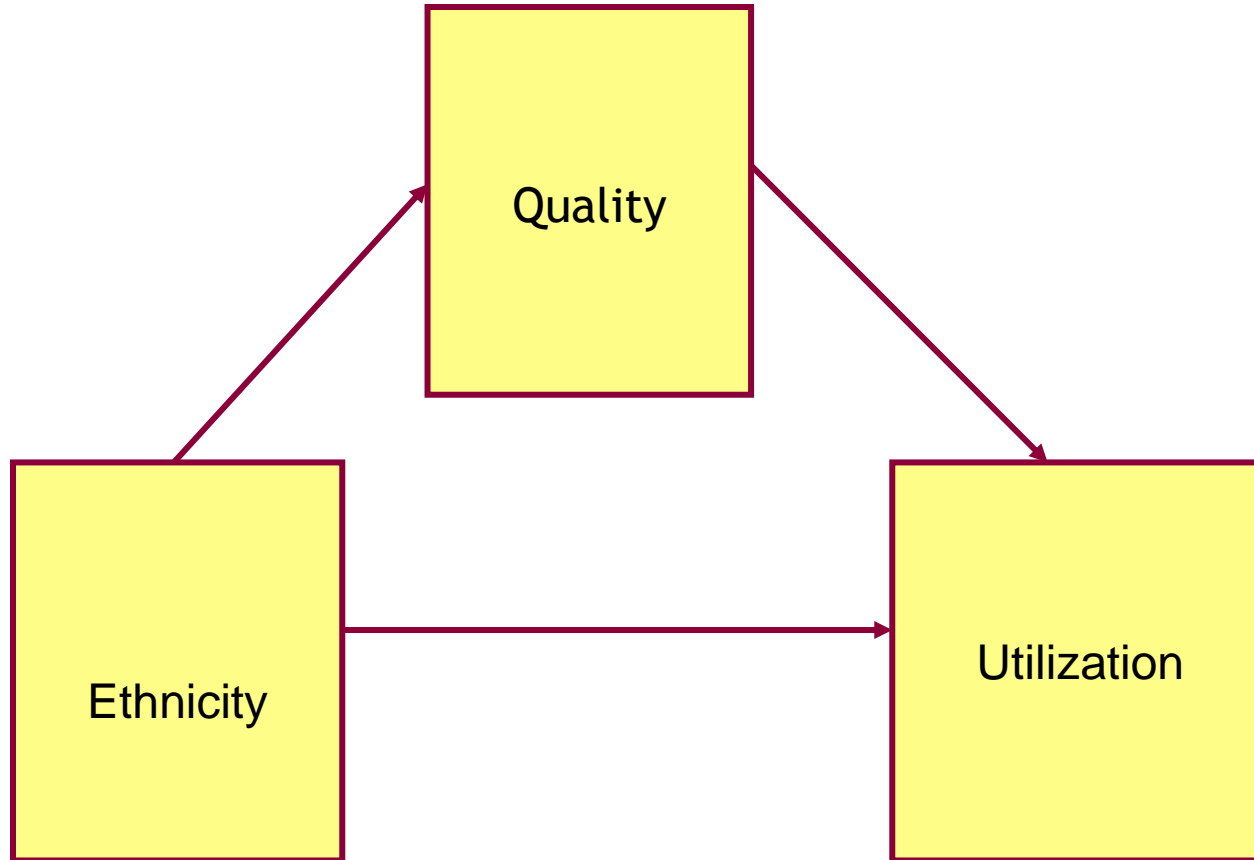


# LATINO CHILDREN AND UTILIZATION





# BETTER QUALITY LEADS TO BETTER UTILIZATION



# MORE EXAMINATION OF QUALITY

- ◉ Disparities between Black and White children for doctor not spending enough time
- ◉ Differences between children with autism and children with other developmental disabilities
  - Black children with autism were less likely to have personal doctor than Black children with other developmental disabilities
  - Black and Latino parents of children with autism were more likely to report that the doctor didn't spend enough time with their child than Black and Latino children with other developmental disabilities

# IMPLICATIONS FOR PRACTICE

- ⦿ Improving quality of health care may improve health care utilization among children with developmental disabilities leading to better outcomes
  - Importance of training in cultural competence among health care providers
  - Importance of training providers in needs of children with specific diagnoses such as autism

# DISPARITIES IN SPECIALTY SERVICES IN WISCONSIN

## ◉ Funding and Support:

- Center on Disparities in Health (CDH), UW-Madison School of Medicine(NIH Center Grant)
- UW System Institute on Race & Ethnicity
- Hilldale Student Fellowship Program
- Waisman Center

## ◉ Students:

- Maria Hernandez, Martha De Leon, Holly Morton, Arellys Aguinaga

# BACKGROUND

- ◉ Little research exists- shows disparities in age of diagnosis and services between Whites and Latinos/African Americans
- ◉ Link & Phelan argue that social conditions are the fundamental cause of disparities in health outcomes and services
  - A major premise of their theory is that a superior collection of flexible resources held by more privileged individuals and the social networks to which they belong allow them to have better health outcomes
  - There is a build-up or accumulation of affects so that access to certain networks and resources gives one access to other resources

# Conceptual Model for Service Disparities

## **Social Conditions**

SES

Race/ethnicity

Gender

Immigration Status

## **Cultural & Environmental Context**

Racism/discrimination

Child with disability

Immigration stress

Values & beliefs

Neighborhood

Language

## **Flexible Resources**

Money

Knowledge

Power

Prestige

Beneficial social connections

## **Access to and utilization of interventions and services**



# METHODS: SAMPLE

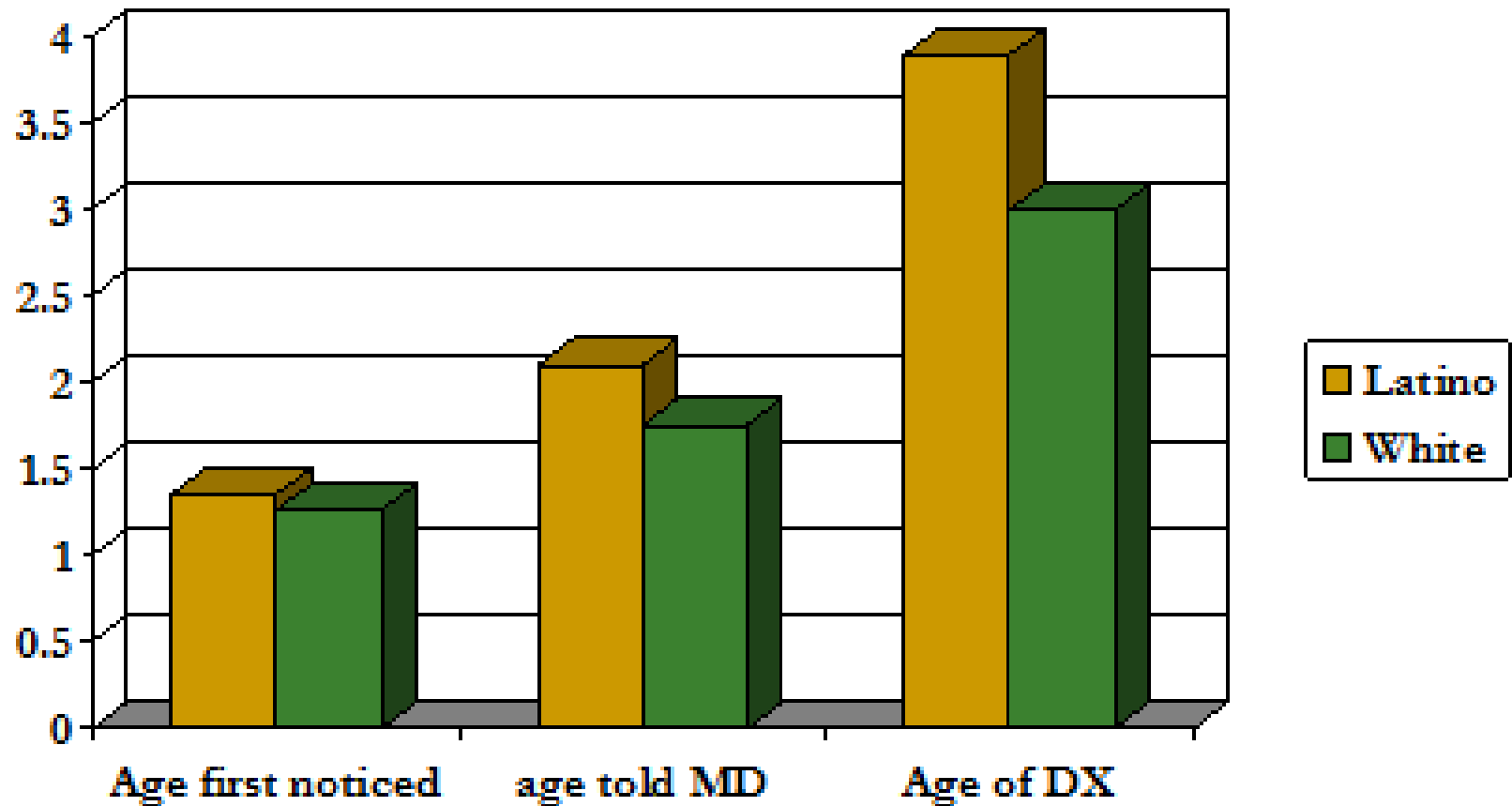
- ◉ Surveys: 105 total
- ◉ 46 Latina mothers
  - Data collected as part of larger study with in-home interviews
  - Recruited through service providers and support groups
- ◉ 59 non-Latino White mothers
  - Mail survey on service questions
  - Recruited through services providers and organizations
- ◉ Significant differences in SES between 2 groups

# MEASURES

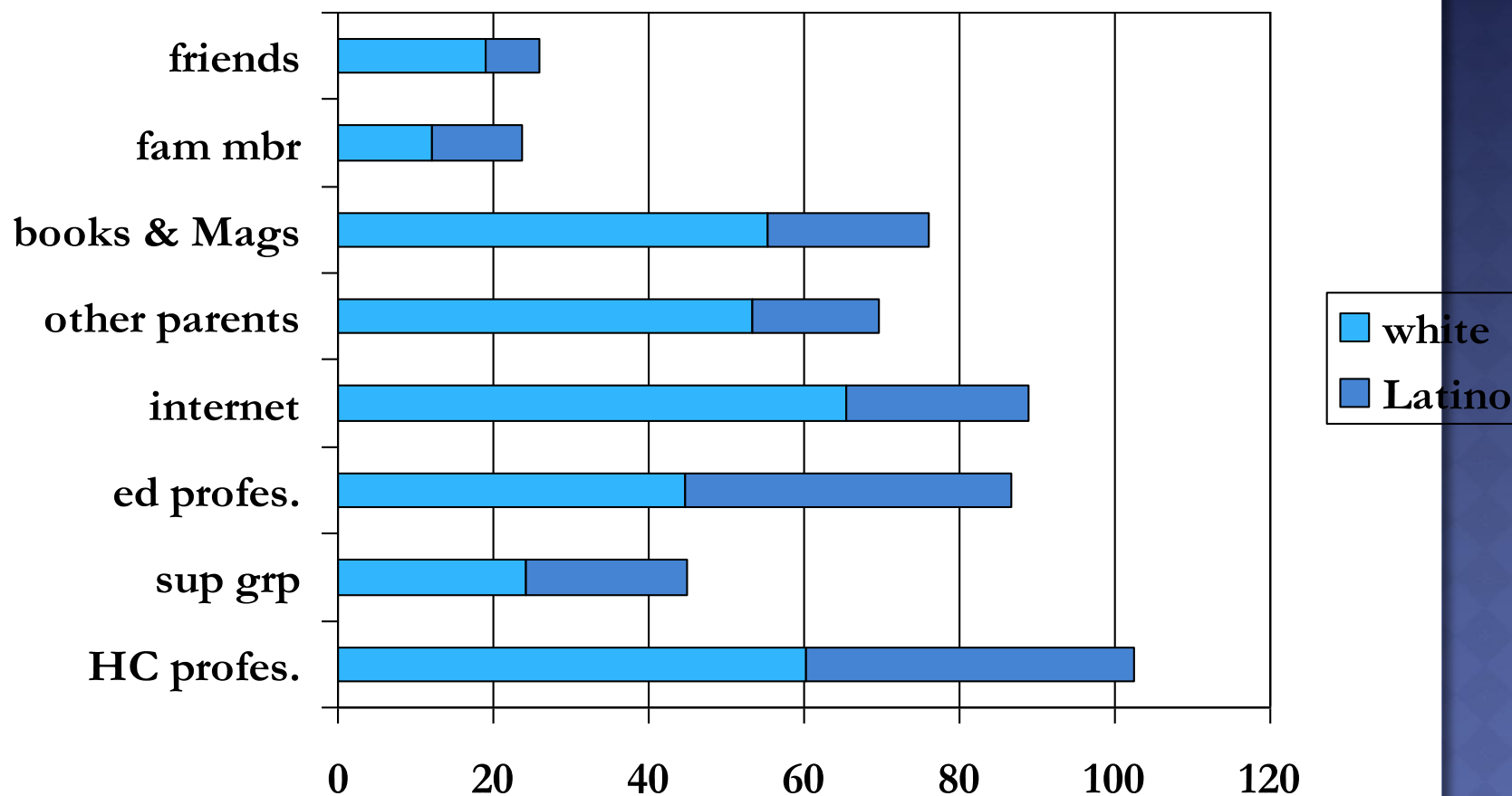
- ◉ Questionnaire about diagnosis, doctor's responses, services
  - Some items from a survey from David Mandell
  - Other items from questionnaires developed by Marsha Seltzer and Marty Krauss
  - Maladaptive behaviors- Sib-R:
    - Scales of Independent Behavior Revised
    - Bruinicks, Woodcock, Weatherman, Hill
    - Count of 8 behaviors



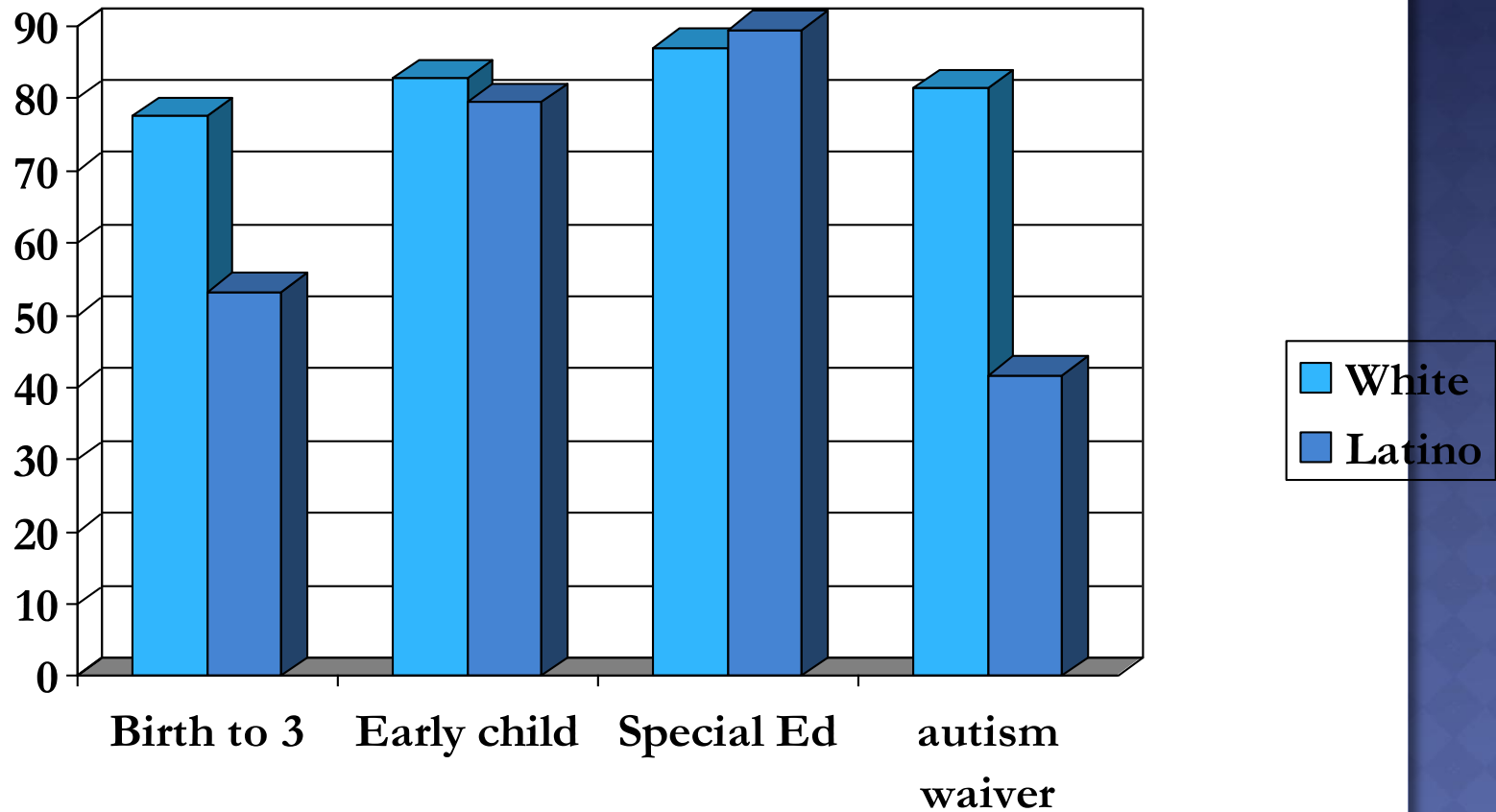
# Age of diagnosis



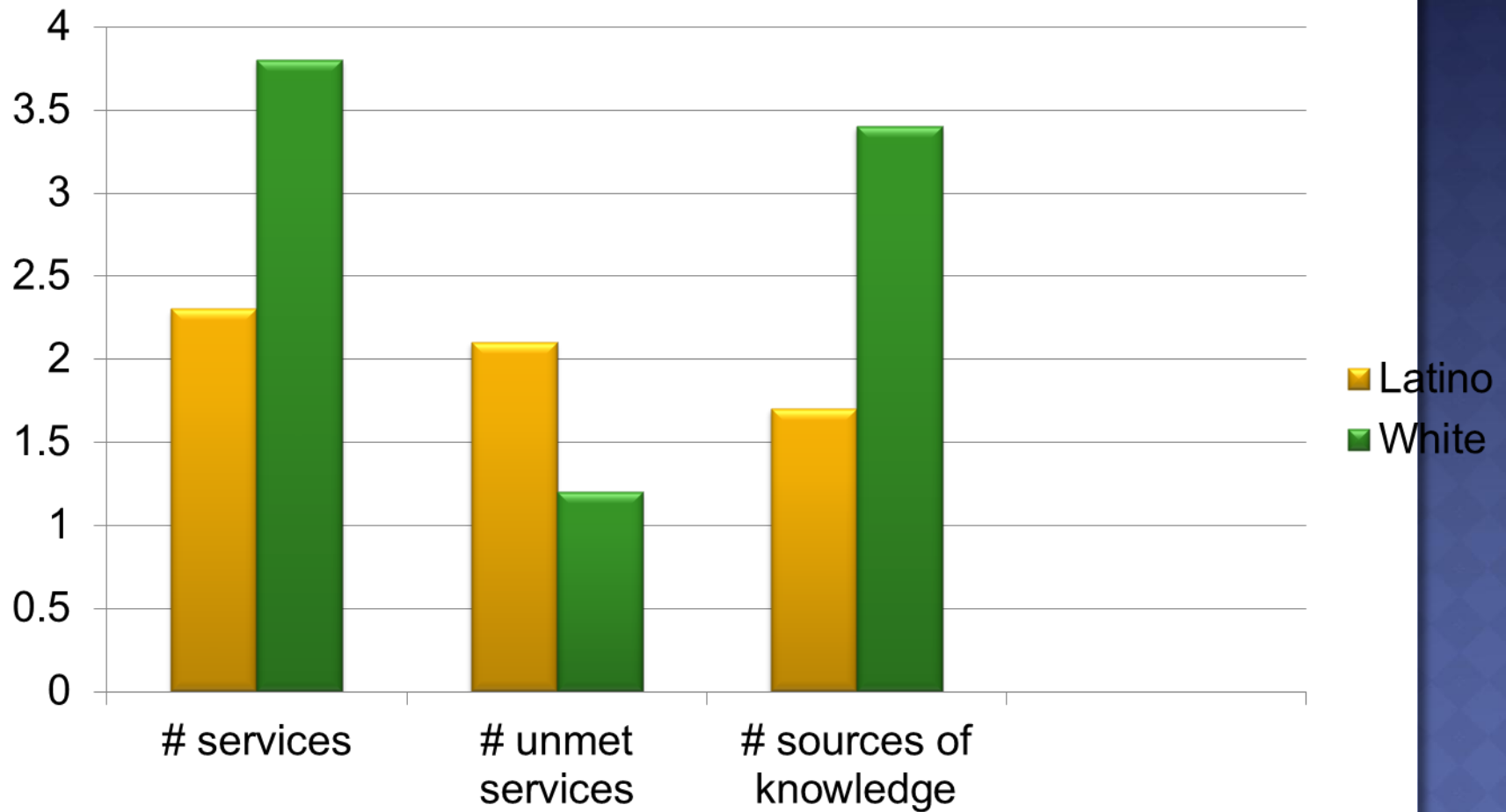
# FAMILIES LEARNED ABOUT AUTISM FROM



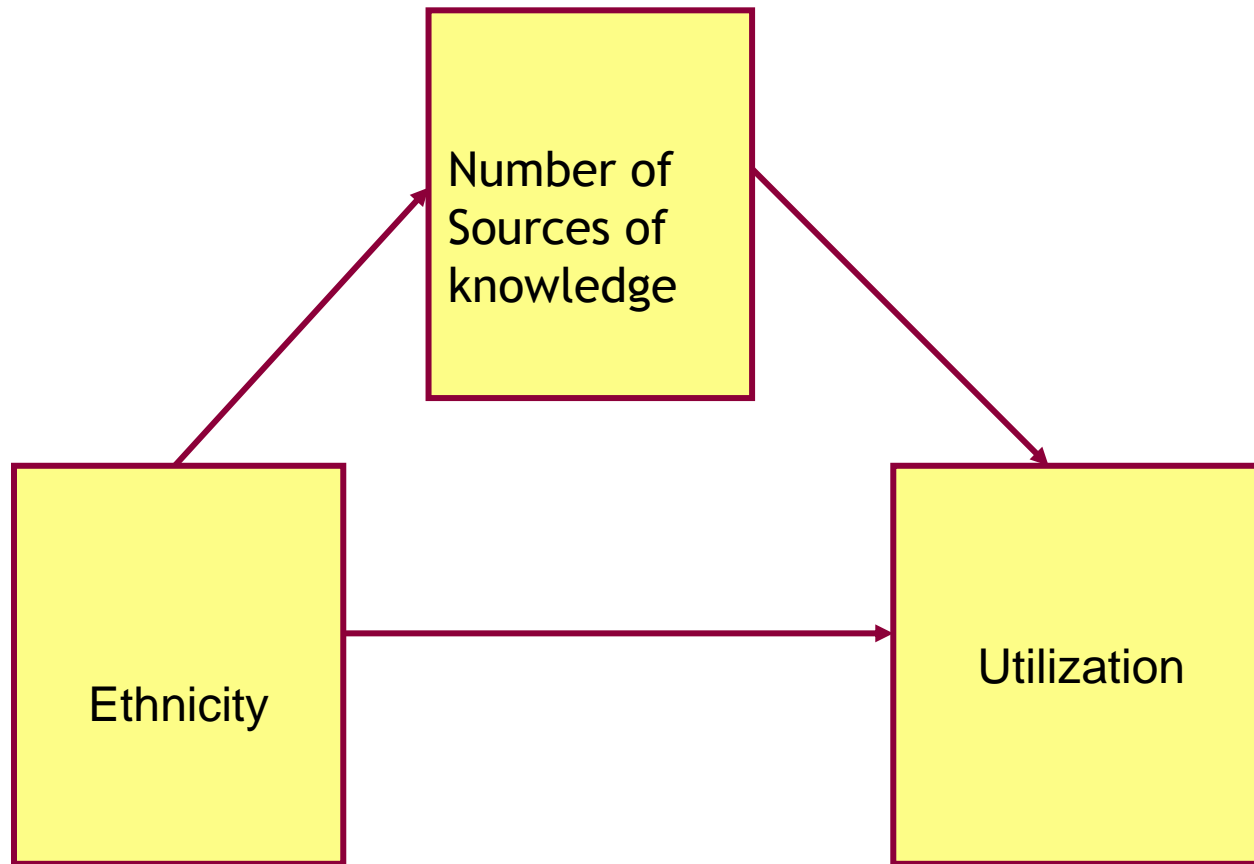
# KEY PUBLIC SERVICES IN WISCONSIN: EVER RECEIVED



# SERVICES AND SOURCES OF KNOWLEDGE



# GREATER SOURCES OF KNOWLEDGE LEADS TO HIGHER SERVICE USE



# EDUCATIONAL INTERVENTION

- ◉ *Entendiendo el Autismo, Puedo Entender Mejor a mi Hijo (By Understanding Autism, I Can Better Understand My Child).*
  - Funded by UW Madison's Institute on Clinical and Translational Research (ICTR)
  - Community Partner: Wisconsin Family Assistance Center for Education Training and Support (WI FACETS)
- ◉ Co-PI
  - Wendy Machelicek from Rehab Psych & Special Ed
- ◉ Students
  - Rebecca Paradiso and Arellys Aguinaga

# ADVISORY COMMITTEE

- ◉ Latino parents of children with autism; local social service and medical professionals who work with Latino families; autism educator Emily Iland; research and FACETS staff
- ◉ Met several times to review and give feedback on program content
  - Will continue to meet throughout course of project



# ADVISORY COMMITTEE





**Ceremony for Completion of  
Program Training**

## PROMOTORAS DE SALUD

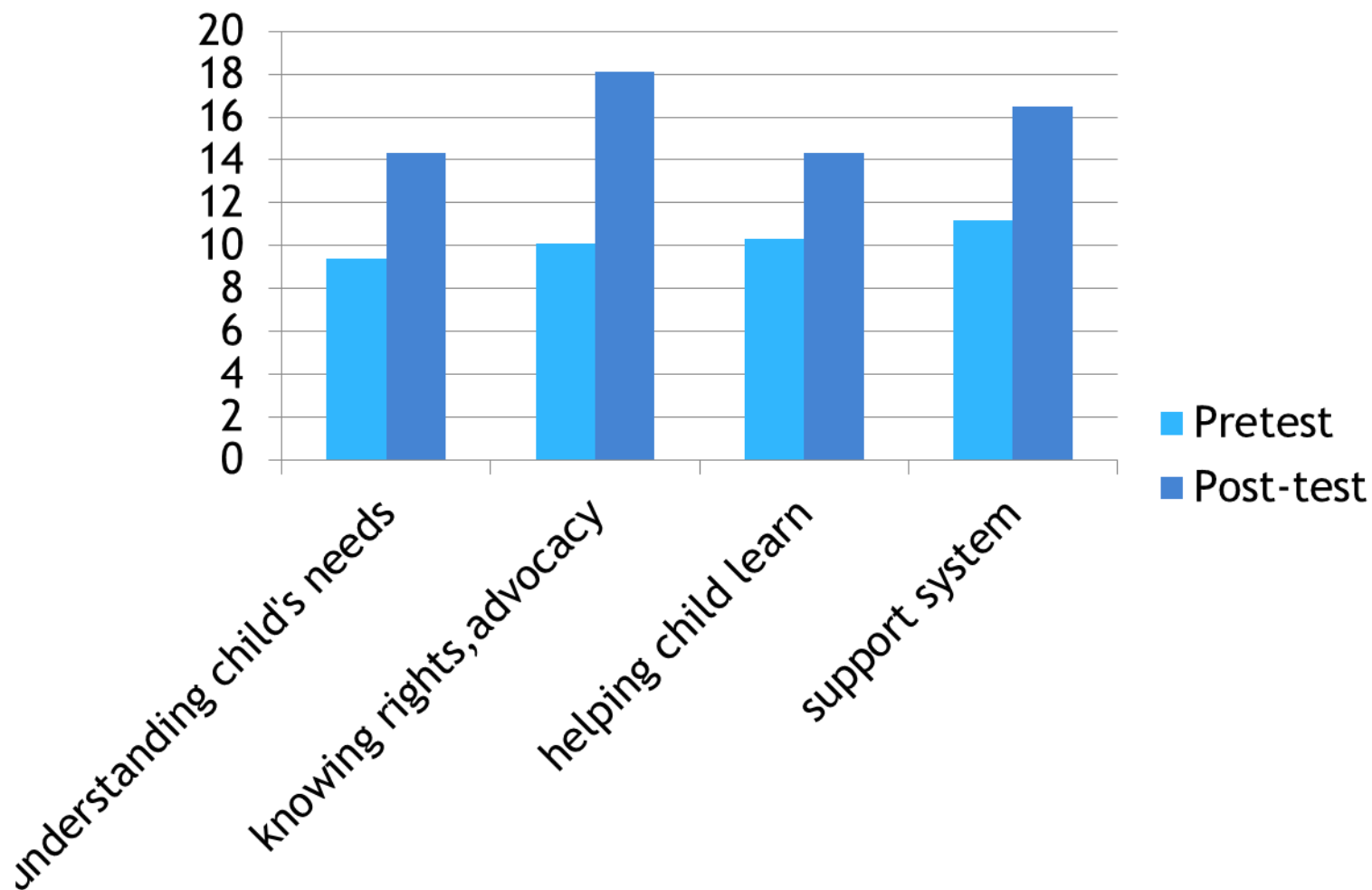
### Unique approach

- Hired 3 mothers of children with autism
- Received intensive training in Spanish to review program content
- Conduct home visits with participants

# DESCRIPTION

- ◉ Program consists of 2 modules; each have 8 weeks of content
  - 1 session administered/week
  - Each session approximately 1 hour long
  - Sessions includes activities, discussions and home work assignments
- ◉ First Module
  - Focus on child development; understand an autism diagnosis; learning about available autism resources and services; and explaining a child's behaviors to others.
- ◉ Second Module
  - Focus on strategies parents can do to work with their child on enhancing social and communication skills and reducing problem behaviors

# MODULE 1 PRELIMINARY RESULTS



# SECOND MODULE SESSIONS

- ◉ **Session One: *Introduction and Pre-test***
- ◉ **Session Two: *Learning About Research-Based Interventions***
- ◉ **Session Three: *Play Skills***
- ◉ **Session Four: *Social Skills***
- ◉ **Session Five: *Communication***
- ◉ **Session Six: *Understanding Behavior Problems***
- ◉ **Session Seven: *Preventing and Reducing Problem Behaviors***
- ◉ **Session Eight: *Looking Ahead and Post-test***

# CHALLENGES FOR 2<sup>ND</sup> MODULE AND NEXT STEPS

- ◉ Module 2 challenges

- More complex material for promotoras to convey
- Worked to make it interactive and more visual
- In the process of finalizing manual and training

- ◉ Next steps, adapting intervention to other underserved groups

# CONCLUSION

- ◉ Evidence of disparities
  - in health status of caregivers
  - health care access, quality and utilization among children with developmental disabilities and autism
  - Specialty services for children with autism
- ◉ One way to address is through educational/empowerment programs delivered by peer leaders

QUESTIONS?